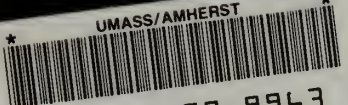


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REPORT:

**Needs Assessment and the Development of an
Ongoing Monitoring Process**

Prepared for:

▲ Holyoke/Chicopee/Westfield HIV Care Consortium
River Valley Counseling Center
Lead Agency

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HOLYOKE/CHICOPEE/WESTFIELD
NEEDS ASSESSMENT REPORT

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HOLYOKE/CHICOPEE/WESTFIELD

BACKGROUND

The Donahue Institute was hired by the Holyoke/Chicopee/Westfield HIV Care Consortium, with River Valley Counseling Center as the lead agency, to conduct a needs assessment focusing on existing resources and changing needs in the communities served, and the capacity of service providers to meet these needs. The results of the needs assessment, presented and analyzed in this report, have been incorporated into recommendations for ongoing Consortium activities, including ongoing monitoring and evaluation.

The objectives of the needs assessment are:

- to systematically review the needs of individuals and families with HIV in the H/C/W Consortium catchment area;
- to monitor the ability of existing programs to meet those needs;
- to develop programmatic responses to address unmet needs; and
- to develop systematic data collection and analysis processes to be used for future program development and ongoing monitoring of Consortium service delivery and consumer needs.

METHOD AND SAMPLE

Approach.

The study utilized a qualitative, exploratory approach, designed to gather detailed information from a small sample, rather than a quantitative approach and a large sample. Interviews and open-ended questions were utilized to gather information rich in detail.

Although a standard survey instrument with specific items and scaled responses would have simplified both administration and analysis, much of the detail would have been sacrificed. Rather than deciding beforehand what the answers would be, open-ended questions enabled the respondents to raise salient issues and concerns rather than react to a laundry list of choices. The result is a far richer data set obtained from a small number of respondents, providing qualitative detail impossible to obtain from a scaled survey questionnaire administered to a large sample.

Instrument design.

The development of the needs assessment process began with structured interviews with the Consortium Co-Chairs, lead agency representative, and a handful of key provider staff who participate in Consortium activities. The purpose of these interviews was to assist us in framing the issues for the development of specific research questions and instruments. During the course of the needs assessment, Donahue Institute staff have attended regular Consortium steering committee meetings, as well as planning meetings and a meeting on monitoring and evaluation of Consortium activities with representatives from the Department of Public Health.

A total of four data collection methods were utilized:

- Telephone interviews with provider representatives
- Individual questionnaires for consumers and consumer advisory board members
- Individual questionnaires for case managers
- On-the-street questions for at-risk sex industry workers

Three questionnaires, one for providers, one for case managers and consumers, and one for people at risk for HIV, were developed in draft form and revised, based upon feedback from case managers and Consortium representatives. The questionnaires were translated into Spanish by bilingual, bicultural translators. Copies of these instruments appear in Appendix A.

The questions contained in these instruments will be attributed with scaled responses derived from this analysis, and incorporated into survey instruments for future administration. The use of quantifiable survey questions will enable the Consortium to administer the surveys to large numbers of respondents, and compare the findings on an annual basis.

Administration.

Donahue Institute staff conducted telephone interviews with representatives from Consortium member organizations, following a structured interview format.

In order to protect consumer privacy, case managers were utilized to collect data from the consumers. Case managers were trained by Donahue Institute staff in questionnaire administration. Attempts were made to incorporate all Consortium case managers in data collection, with each case manager asked to facilitate responses from 3 to 5 consumers.

Consumer advisory board members were asked by the Consortium consumer advisory board liaison to complete the questionnaire. Member organizations were asked to distribute the questionnaire to their own consumer advisory board members, with responses sent to the Donahue Institute via return mail. Few surveys were returned by consumer advisory board members, despite the inclusion of postage-paid, addressed envelopes.

In the process of instrument development, several case managers felt strongly that they and other case managers should complete the consumer questionnaire on behalf of their consumer clientele, in addition to conducting individual interviews with a small number of consumers. Every case manager was asked to complete a consumer questionnaire as part of their training to administer the questionnaire to consumers.

Bridge volunteers from AIDS Allies conduct street outreach in Springfield and Holyoke with sex industry workers who are at risk for contracting HIV. A short set of questions about HIV services was developed for use by the Bridge workers, so that the needs assessment could gauge the level of knowledge and perceptions about services among those at high risk for contracting HIV. The volunteers raised the questions during their contact with Holyoke sex industry workers, with responses recorded after the conversations took place.

Respondents.

A total of 18 provider representatives were interviewed, with 7 of these also belonging to the Springfield Ryan White Consortium. A total of 5 case managers, representing 4 agencies, participated in the training, and 6 completed the consumer questionnaire. Questionnaires were administered to 24 individual consumers, and 3 were returned by consumer advisory board members.

Consumers were not required to provide the demographic information requested on the questionnaire, although most answered a least some of the questions. Demographic information on consumer respondents is presented below:

	# CONSUMERS		# CONSUMERS
AGE		Male	6
19-25	2	Female	21
26-35	14		
36-45	5	CHILDREN UNDER 18	
>45	5	yes	18
RACE/ETHNICITY			
Latino	17	SEXUAL ORIENTATION	
White/non-Latino	9	heterosexual	9
		gay/lesbian	4
IV DRUG USE			
yes	7		
no	12	in recovery	2

Representativeness of the sample.

Consumer participation in the needs assessment was completely voluntary. Case managers were instructed to select consumers who were representative of their overall caseload. However, self-selection, case manager and consumer time constraints and other related issues make it impossible to ensure that the resulting respondent pool accurately represents the total population of consumers within the Consortium.

Consumers who are receiving HIV care services are by definition already in the system, and therefore, have their needs met to a greater degree than consumers who are receiving few or no services. Consumer advisory board members have a voice in decision-making and are arguably more empowered than the "average" consumer. It is plausible to argue that the needs of the overall HIV+/PWA population in the catchment area are comparable or more extensive than those of the respondents in this study.

Sex industry workers are at high risk for HIV, and their HIV status is unknown to the Bridge volunteers who spoke with them. However, their answers represent the perspective of those who are at high risk for HIV and are likely to be alienated from the provider system.

Limitations of the data.

Due to self-selection among respondents, the small sample size, and the use of open-ended questionnaires, it is neither appropriate or possible to draw statistical inferences from the data and generalize the findings across the entire HIV/PWA population. However, the results provide a rich and detailed understanding of the current and emerging needs and service delivery issues facing the Holyoke/Chicopee/Westfield Consortium. The findings can be used as a baseline against which to compare the results of the ongoing monitoring process.

RESULTS

Analysis.

The needs assessment process focused on the collection and analysis of qualitative data. Tables for provider responses to the questions are presented in Appendix B, tables for case manager and consumer responses are in Appendix C, and responses to Bridge volunteer questions appear in Appendix D.

Although these tables contain percentages of responses of a particular answer, it is necessary to remember that these are not response choices to a list of answers. For example, had respondents been given a list of services and asked to check off all those that were helpful, the percentages for each response would have been higher.

The answers to all of the questions represent responses to open-ended questions, in which the respondent was free to raise what was most salient in his or her mind. Rather than collapse the answers into fewer categories to garner higher percentages, we have maintained as many distinct items as possible to preserve detail.

It is also important to note that the responses are based on perceptions, which may or may not be based on facts, falsehoods or myths. Whether a barrier to service actually exists is beside the point when the common assumption is that the barrier is real. A mis-perception may be as problematic and insurmountable in a consumer's mind as an accurate one.

The raw data is nothing more than a summary of actual answers, which have been categorized into common issues. The analysis begins with the raw data, examining linkages among questions, responses within and across consumers, case managers, etc. Interpretation of the results focuses on practical applications to the Consortium, with regard to Consortium services, processes, ongoing needs, and other related issues.

Many issues derived from the data are beyond the scope of needs and services to which the Consortium can respond. Therefore, recommendations will focus on those areas that are relevant and feasible. Member organizations within the Consortium may want to explore additional funding sources and opportunities to address needs that fall outside the scope of supportable activities under the Ryan White legislation.

THE PROVIDER PERSPECTIVE

Utilization.

Member agencies provide a broad array of HIV services, ranging from health and mental health care to case management and supportive services, education and prevention, outreach and advocacy.

Health-related services most in demand appear to be skilled nursing and home health care, and substance abuse treatment. Among support services, case management, transportation, housing and targeted support groups are most in demand.

Under-utilized services focus on home health personal care services, child care and pastoral counseling. Latino families often prefer to perform personal care services for family members, rather than receive these services from a stranger. Respondents suggest that homemaking services would therefore be more beneficial for families who prefer or have the ability to provide personal care services for their loved ones.

The child care process appears to be perceived by some respondents as less "user friendly" than it actually is, and not well-suited in its present form to the needs of consumers. Pastoral care appears to be under-utilized primarily because many consumers do not know of its availability.

Barriers.

Consumer access to services is the major barrier perceived by providers. Issues range from the limited number of doctors in Chicopee and Westfield who treat people with HIV and AIDS, or accept medicaid, to the cost and difficulty in travelling to other communities to receive services. Many consumers are unaware of available services, and often rely on providers who may have limited knowledge themselves.

Low levels of literacy and English language proficiency among many Latinos in Holyoke further impact on knowledge of and access to services. Provider cultural sensitivity and awareness, the lack of bilingual and bicultural nurses and physicians, and community avoidance of coming to terms with the epidemic were all cited as contributory.

Fear of disclosure, and the stigma associated with HIV and AIDS, often delays treatment, particularly among Latino men. The size of the community and the limited number of providers often lead residents within the Consortium catchment area to seek treatment in another city, such as Springfield. Lack of transportation further complicates access to treatment.

Barriers to child care usage focus on difficulties in transporting children to day care en route to the hospital or clinic, misperceptions about how the program operates, reluctance to leave children with strangers, and difficulties in arranging for care. On-site day care at the clinic was suggested as an alternative to the current model.

The Consortium plays a large role in assisting consumers to overcome these barriers, primarily through access to transportation, case management advocacy and inter-agency networking and referral.

New and expanded services.

A wide range of services are perceived as needed to meet the needs of consumers in the catchment area. Providers were asked which services they would expand or add, if more funding were available through whatever source. The responses were not limited to services supported by Ryan White; rather, they reflect the broader needs of people with HIV and AIDS. In a later question, providers were asked which Consortium services they would add or expand.

Traditional and alternative health care services mentioned focused on nutrition, holistic treatment, massage therapy, substance abuse services, and testing and counseling. A few respondents suggested that a registered nurse to coordinate HIV services would improve health care delivery for people with AIDS.

Housing, transportation, supportive counseling and targeted services for specific populations, e.g., mothers with HIV, were cited. Education and prevention was a major target for additional support.

Consumer feedback and participation.

Providers received consumer feedback formally and informally, through surveys and participation on boards and committees and through conversations with case managers and other direct care staff.

Consumer feedback ranged from negatives, such as frustration about the bureaucracy, regulations, waits for treatment, and complaints about where all the money was going, to specific needs, such as transportation and housing. Positive feedback focused on the way services helped consumers.

Over half of the agencies actively engaged consumers in participation on boards, committees or councils. However, most providers spoke to frustration in recruiting new consumers, and the difficulties in keeping consumers involved.

Suggestions for increasing consumer involvement ranged from the need for empowerment and greater decision-making responsibility to formal community service and outreach programs utilizing consumers.

Community outreach.

The primary community outreach mechanisms mentioned by the providers focus on education and prevention rather than service provision. Consumer empowerment through community service in an outreach capacity would expand the current outreach methods utilized across the Consortium.

Service delivery issues.

Member agencies face a broad array of service delivery issues, ranging from access and resources to staffing patterns. Adequate funding and reimbursement to provide necessary services was a major concern, as was the lack of health care providers in Chicopee and Westfield.

The growing Latino community raises many issues, such as the difficulty in finding and retaining reimbursement-eligible bilingual and bicultural health care workers. Provider training in the areas of cultural awareness and knowledge of available services were seen as necessary.

Consumer knowledge of available services, coupled with the limited number of providers in Chicopee and Westfield, highlight the need for the Consortium to be proactive in planning how to meet the growing numbers of consumers in these communities.

Other issues facing the Consortium were mentioned, such as the need for flexibility and willingness to change according to needs, turf issues around money and services, and tension about the amount of money spent on administration rather than for direct service delivery.

Virtually all the providers agreed that the demand for services has increased over the past few years, while the amount of money available to provide services has been cut or remained the same. However, many improvements over the past five years were mentioned by members of both Consortia. These benefits include better cooperation among providers, more teamwork, and improved information sharing. Negatives focused on more turf issues and more frustration. A later section focuses specifically on benefits of Consortium membership.

Current and emerging needs.

The most pressing community needs focused on access, health, environmental and social concerns, and education. Expanded local services, continuity of care, cultural and language barriers, counseling and mental health, and services for dual diagnosis of substance abuse and HIV were mentioned frequently. HIV education, transportation and housing were seen as crucial needs, as were other support services. The need for cultural sensitivity training for providers was cited.

Supported education, training and day care to get off of welfare, outreach and prevention were also seen as critical needs, particularly for Latinos. Outreach to parents and adolescents was seen as essential, particularly around prevention issues.

Provider suggestions on how to better address these needs focused on coordination of services, expansion of institutional resources, provision of supportive services, more resources for the Consortium, and increased community ownership of the issue.

Providers covered a very broad range of needs they see emerging over the next five years. The need for home health care and long-term care options were seen as a result of more people with HIV and AIDS living longer.

Other associated needs were projected to rise as a result of growing numbers. Agencies with small HIV caseloads were concerned about their capacity to meet the growing demand for services. Many providers expressed fear that the growth in numbers, coupled with limitations on health care delivery, reimbursement and rationing, would create gaps and impact access to care.

Rising numbers of families with HIV and projections of orphaned children highlight the lack of institutional resources and policies to deal with these issues. As the numbers grow, and the life expectancy increases, housing becomes even more critical.

Consortium issues.

Consortium membership was perceived as benefiting both consumers and providers. Providers found their consumers benefited through access to Consortium services and funds. Providers benefited through information sharing, networking, collaboration and staff support and training.

Proposed changes in the way the Consortium operates focused on four categories: resources, structure, consumer needs and services. With regard to resources, better monitoring of money and access to more money were most frequently mentioned. While one provider thought less should be spent on administration, another thought that more should be spent on oversight!

Under structure and process, greater consumer involvement, less duplication of services and broader representation of providers were cited, as was standardization of services. Consumer awareness of services available through the Consortium was seen as critical.

Providers emphasized that they must keep track of the changing needs of diverse populations; they suggested utilizing case manager input as well as consumer involvement to track needs.

The limited availability of local services, and the small number of physicians with experience treating people with HIV and AIDS, speak to the need for expanding services beyond what already exists in the Consortium, particularly for Westfield. Services are discussed in greater detail below.

Providers were asked how they would target additional Consortium funding. Responses ranged from health care to staffing, allocation of funds, support services, outreach and education/prevention. The need for a better day care model was raised, due to the under-utilization of current funding. It is important to note that providers did not discount the need for day care funding. Rather, they focused on its current delivery as the problem.

Services targeted for increased funding include transportation, home delivered meals, vitamins and over-the-counter medications, support groups, consumer community service, and outreach. Other services cited, beyond the realm of the Consortium, are legal services, home health care, nutritional support and housing mediation.

Providers raised a number of additional issues related to the Consortium, focusing on the day care model, consumer and provider issues, resources, politics and the community. Perhaps the most important comments focus on questions about consumers, the Consortium and provider issues.

Consumers were seen to have limited knowledge about available services, often due to lack of communication between consumers and providers, and misinformation and misperceptions about HIV. The need to involve consumers in the delivery of services was seen as critical.

In this question and earlier ones, providers raised the need for coordination of services, standardization of case management functions, and oversight of resource allocation, particularly for transportation.

With regard to providers, turf battles and politics were seen as sometimes impeding service delivery. Private doctors were seen as unknowledgeable about HIV and AIDS, and available services. Earlier referrals were seen as necessary.

THE CONSUMER AND CASE MANAGER PERSPECTIVES

The needs assessment examined the consumer perspective through feedback from case managers, consumer advisory board members, and the consumers themselves. Case managers provided their own impressions on both consumer needs and the current delivery of services. Although the numbers themselves are small, the issues raised shed much light on the needs and issues facing people with HIV and AIDS.

The final results section, which follows this one, provides the perspective of people who are thought to be at high risk for contracting HIV, and are not likely to be receiving services at this time.

Awareness of services.

Consumer awareness of available services was seen to vary greatly. As one consumer put it, "I am one of the few consumers who knows all of the services available to them, and knows how to [access] them." Other consumers and consumer advisory board members thought that consumers were somewhat or even well-informed.

Case managers thought that most people with HIV/AIDS are aware of services, but that few are aware of all of the services that are available to them. Case managers also indicated that consumers become aware of services primarily after intake at an agency.

The consumers who completed the questionnaire were already receiving services through the Consortium or other providers, and therefore had greater knowledge than someone who was not "plugged in." Similarly, the case managers' role included informing consumers about available services. It makes sense, then, that they considered consumers to be fairly well-informed about some available services.

Getting the word out.

Consumers learned about available services through formal means, e.g., meetings, case manager instruction and support groups. Social workers and health care providers were less often conduits for information. When ill, consumers were more reliant on learning about services from medical sources, e.g., clinics, treatment centers, doctors and nurses.

Informal lines of communication included word of mouth, through friends, families and other persons with HIV/AIDS. Consumers also learned about services proactively through asking questions at appointments with caregivers and reading available material.

Consumers infrequently cited media as a way people with HIV and AIDS currently learn about services. However, when asked how providers can get the word out about services, consumers frequently suggested using flyers and brochures, television and radio. Newspapers and posters were also mentioned. However, for consumers who cannot read, oral announcements are necessary.

Consumers raised the idea that they, themselves can take an active role in informing others with HIV and AIDS about available services. This could be accomplished through informational meetings, outreach mechanisms, or a consumer-run office for advocacy, information and referral.

Case managers saw flyers and brochures as a mechanism for providers to inform to consumers. Newspaper advertisements and public service announcements were seen as ways of disseminating information about HIV and AIDS. However, cultural and linguistic sensitivity must be employed.

Other suggestions were that providers use a variety of support services to inform consumers of services, such as, support groups, consumer meetings, workshops, committees and task forces. Focused outreach and community training were cited as ways to improve knowledge of available services.

New or expanded services.

Consumer responses to what services they would like to see offered or expanded were not limited to the parameters of the Consortium. Rather, they reflected broader needs of people living with HIV and AIDS.

Increased case management and information and referral about services and health care options were desired by consumers. Consumers also sought coverage for vitamins and over-the-counter medications, expanded nutrition and home delivered meals, and access to the emergency food bank. The need for more doctors and dentists trained and willing to treat people with HIV and AIDS was seen as critical.

Child care services were cited for expansion, despite their current under-utilization. This finding supports the providers' contention that the current model is not working as it was intended. Support for families with HIV+ parents, and volunteers and staff to transport consumers to appointments were also targeted.

There was consensus around the need for a recreational center, where people can congregate for support, information sharing, etc., and talk openly about living with AIDS.

Housing was seen as a major need, both in terms of access and supply. Shelters were not seen as a viable substitute; consumers want homes for themselves and their families. The need for substance abuse treatment and programs for the dually diagnosed was cited.

Prevention education, particularly in Spanish, was also targeted. Women's health services, holistic health care, and financial assistance (rent, utilities, deposits, and emergency money) were also cited as in demand.

Case managers would like to see new or additional funds spent on transportation, financial assistance, prevention education and intervention, and child care. Case managers who run support groups cited the difficulties in running a group amid the distractions of children. The presence of on-site child care would remedy this problem.

Case managers most frequently cited HIV/AIDS educational materials in Spanish as a major need. Other needs cited include support groups in English, bereavement counseling, stress management, bilingual services, funeral expenses, and a volunteer coordinator.

Most and least helpful services.

Consumers did not limit their responses to services provided by the Consortium. Among Consortium services, consumers frequently mentioned transportation, case management services, counseling and home delivered meals as the most helpful. Other helpful services mentioned were housing, health care, medication, and education on new medical services and drugs.

Consortium services seen as least helpful were child care services and services targeted for specified ethnic groups or races. Other services seen as least helpful were DET, Welfare, DSS, and housing.

Consumers reported that long waiting lists and intrusion into personal lives makes it difficult to access services. Some consumers want more services accessible to them and feel frustrated. "I am angry at what is in place in this area. Too much talk, not enough action."

Another consumer complaint is that AIDS information is everywhere, but it is not effective in reaching those who need it most. New or different kinds of information or approaches are seen as necessary in order to get the message across to larger numbers of consumers.

Case Managers agree with consumers about the most helpful services: home delivered meals, transportation, support services, medical services (including home health care), and housing. Although housing and transportation are considered to be very helpful, the waiting lists are seen as problematic. Translation and interpretation services were also cited as helpful.

Supported child care was cited as least helpful by several case managers, because it is under-utilized. Suggestions were made to reallocate its funding to other more pressing areas, or to find a better child care model that will be utilized by numbers of consumers.

Service gaps and needs.

Consumers frequently cited the need for a caring relationship with their case managers. Some consumers felt that there was not enough time to develop in-depth relationships, to find out about the available services and discuss issues facing people with HIV and AIDS. Several consumers stated that more bilingual, bicultural counselors were needed.

Involvement of consumers in the service delivery system was seen as crucial. Consumers cited the need for more services in Holyoke, Chicopee and Westfield, and more support groups in accessible locations within these towns. Other needs mentioned were support groups in English, child care, individual counseling, an information hotline, and a buddy program.

The need for more housing, emergency housing, and better maintained housing was stated frequently. Several consumers said that they are, "...afraid to live [in rodent and insect infested housing] because of the diseases from the pests. HIV people [are vulnerable to] getting sick from them." Other needed services were: emergency and non-emergency financial assistance, interpreters, holistic care and education/prevention. Women's services that are not targeted by race or ethnicity was cited as needed.

Case managers most frequently noted transportation and housing as the greatest needs. Other needs cited include: parent training groups, bereavement counseling, training for consumers on accessing services in the current system, nutrition education, foster care for children of parents with HIV or AIDS, culturally appropriate translation services, and dual and diagnosis treatment services.

Barriers and solutions.

Consumers most frequently cited lack of transportation as the barrier to getting services. For many Latinos, lack of English proficiency was cited as a major barrier. Lack of knowledge about services and unavailability of timely information were also barriers facing consumers.

Isolation among consumers and lack of community support were also seen as barriers. People who have an HIV+ diagnosis often feel rejected by others. Fear of what others say and think leads to avoidance of disclosure and isolation. People with AIDS may have low self-esteem and be afraid to ask for things they need.

Some consumers considered a poor interagency referral system and little coordination of services to be a barrier, caused by the allocation of funding to agencies that are not equipped to deliver services. Other consumers stated that limited funding for HIV/AIDS and poor management of agency funds interfere with the delivery of services.

Consumers perceived that limited funding means reduced staff time spent with consumers. Case manager caseloads were seen as too large to allow much personal contact with consumers. Increased staffing, home visits by case managers, and social workers with greater understanding of living with HIV and AIDS were seen as solutions to many of these barriers. Improved information and referral services and inter-agency coordination were also proposed by consumers as solutions.

Case managers also cited many obstacles to service delivery. Substance abuse, lack of money for housing and health insurance, poor nutrition, and fatigue were cited as obstacles facing consumers.

Consumer awareness of available services was seen as critical. As one case manager said, "Consumers are only aware of the services they currently need, most of the time." Information that is inadequate, out of date, and easily misunderstood also impedes access to services.

Clear, timely information that is culturally and linguistically appropriate would improve access to services. Staff support and increased use of volunteers would ease the burden on case managers. Provider training in cultural sensitivity was seen as needed.

Consumer Input.

Meetings were seen by consumers as the place to voice concerns. However, some respondents said that agencies don't listen to consumers, so many consumers don't bother coming or speaking up. Increased meetings between providers and consumers was seen as needed to improve communication.

Consumers suggested the utilization of designated consumers to facilitate the smooth flow of information between consumers and providers. In this model, consumers would represent other consumers, assimilating concerns and expressing needs and wants.

Consumers provide verbal feedback to doctors, case managers, psychologists and legal service personnel. Many consumers cited active ways of voicing concerns: writing to politicians, joining community and volunteer groups and consumer advisory boards, self-education, and verbal and written communication.

Other suggestions included hiring people knowledgeable about HIV/AIDS, including consumers, to work with consumers to disseminate information and listen to feedback.

Case managers expressed that they could provide a voice for consumer concerns, as an intermediary between their consumers and their agencies. They suggested that agencies solicit consumers opinions on facilities, prevention efforts, health care and support services. They thought that, if agencies demonstrated that they listened to and utilized consumer feedback, consumers would be encouraged to provide input. Case managers also cited the need for consumers to participate on consumer advisory boards and attend consumer and Consortium meetings.

Coordination of services.

Consumers thought improved service coordination would occur through better communication among providers, case managers and consumers. Consumers thought more face-to-face meetings were necessary to achieve this goal.

Improving the quantity and quality of interaction between consumers and providers was seen as essential. Many consumers stated the need to talk openly to providers, to bring up issues, and share feelings about their experiences. Consumers felt they need to actively alert providers about needs and issues.

Consumers suggested that improved coordination would also result from increased numbers of consumers working in the system, with more decision-making power to implement change.

Increased advertising and education about available services and consumer education about the political pressures attached to funding sources were also seen as ways to improve coordination of services.

Case managers suggested that improved networking among agency leaders and agencies that provide services would lead to better coordination of services. Giving consumers more power in decision-making was also seen as a way to improve coordination. Case managers cited the need for increased consumer input on needs in the allocation and reallocation of funds for current and future services.

Changing the system.

Many consumers focused on the need for additional staffing, with an emphasis on hiring consumers to work in the system. Consumers reinforced this concept throughout their responses. Consumer involvement, whether formally, as an advisory board member or paid staff, or informally, through voluntary community service, was seen as providing a sense of purpose and empowerment and enhancing self-esteem. As one consumer said, "I want to help other sick people, make it easier for them to come out, [to] get help, get treatment. *Understanding is needed.*"

Consumers also raised the need for professional staff to develop more empathy and sensitivity towards people with HIV and AIDS.

Case managers had a different emphasis than consumers. Their focus was on the need for more supervision, staff burnout prevention, consumer/provider meetings, foster care, additional resources and information sharing.

Unanswered questions.

Certain items on the consumer questionnaire came back with frequent blank or "Don't Know" responses. Most of these questions asked consumers to analyze their experience in the system and make suggestions about improvements.

A few case managers and consumers were contacted for follow-up interviews to help interpret these gaps in responses. Their thoughts are summarized below.

1. Least helpful services. All services being received are likely to be perceived as helpful. Most consumers only know about the services they need at the time. In Holyoke services are limited, so you have to go to Springfield for many services. Some consumers may fear retribution or loss of services if they complain.
2. Services needed that are not currently available. A lot of consumers do not know enough about HIV/AIDS to know what is needed or what is available. Some may not be able to articulate what they know, even though they know a lot about services. Many consumers are not educated so they might not understand the question.
3. Access to services. Case managers do not always know about all services, nor will the consumers on their case load. Some clients are not aggressive about obtaining HIV information, and they rely on case managers. Sometimes consumers do not ask for HIV literature because of fear of disclosure. Some consumers are very grateful for what is available for services and they do not feel worthy enough to have things easier.

4. Voicing consumer concerns. Some agencies cannot make changes based on consumer suggestions, and this discourages consumers. Often, consumer advisory board membership is a way to get your voice heard, but because of confidentiality, you cannot give new clients' names to the board. Case managers sometimes do not encourage consumers to participate because they think the consumer is not educated enough to join. Some people think changes won't happen so they chose not to answer the question. Some people just did not understand the question.

5. Improved service coordination and delivery. The question was too abstract, not concrete enough. Most consumers know little about services, or how to improve them. Case management time is short and precious so not much is explained about the service delivery system. Latina women are not allowed to express the needs of the family; the men do that. Latina women are not used to answering questions like that. Many consumers have low self-esteem and low education levels, which may make it difficult to express their thoughts on the matter.

OUTSIDE THE SYSTEM: PEOPLE AT RISK FOR HIV

Bridge volunteers provided feedback on their brief conversations with sex industry workers on the street in Holyoke. Interviewees were asked what they had heard about HIV services, through word of mouth or through people they know who have HIV or AIDS. Although the number of respondents is small, the answers are telling.

Awareness of services.

The most common way the respondents thought people learned about HIV services was by word of mouth. Various forms of media, e.g., newspapers, television, and pamphlets were also seen as ways to get information. Some respondents thought that fear might keep people from learning about services until after infection, at which time providers would give out information.

Service delivery.

Feedback received from people with AIDS was often negative. Staff rudeness was a problem, and consumers said they did not feel respected. Insufficient information about available services was seen as a problem.

Most respondents stated that they do not know anyone with HIV/AIDS, so the question is not applicable. In a follow-up interview with some of the Bridge volunteers, they said that many sex industry workers are in denial about the risks of their own behavior. They were not surprised that many of those interviewed denied knowing anyone with HIV or AIDS.

Getting the word out about services.

Several of the respondents cited the need for different media approaches and more printed information. Word of mouth appears to be the most frequent method of sharing information. Since the interviewees are not hooked into the system, there needs to be a way to get accurate, up-to-date information within their reach.

Barriers to service.

Most of the interviewees said that they do not know what barriers get in the way of accessing HIV/AIDS services. Those who answered the question cited lack of money, lack of health insurance, bigotry and ignorance about people with AIDS. They also mentioned procrastination about getting tested and accessing services, reluctance to accept services, and the inability of agencies to force services on the unwilling.

DISCUSSION AND RECOMMENDATIONS

The quality of services provided by the Consortium is a function of the amount of resources available to address specific needs, coordination and information among agencies, the availability of services within the catchment area, and consumer awareness of services. The Consortium faces several issues as it strives to address consumer needs.

Increasing consumer awareness of services available to persons with HIV and AIDS is critical. Given that the knowledge base of consumers already in the system is limited, information about services among others with HIV and AIDS, including the newly diagnosed, is likely to be poor. A coordinated resource and referral mechanism, with information accessible to those with limited English language proficiency and/or reading ability, is essential to increase consumer knowledge of, and access to, available services.

Service delivery is limited by the small number of providers and practitioners in Holyoke, Chicopee and Westfield who are experienced in treating people with HIV and AIDS and are knowledgeable about services. Cultural awareness and sensitivity among providers is an ongoing concern, as is the need for bilingual/bicultural staff.

As the numbers of persons with HIV and AIDS continue to increase, the need for local services will rise. Transportation costs comprise a large portion of Consortium dollars. The establishment of services in Chicopee and Westfield is essential to keep transportation costs within a feasible range. Support groups are also needed in these communities. Agencies in these communities will require assistance from the Consortium in meeting the growing numbers of persons with AIDS in their caseloads.

Provider agencies are often understaffed; as caseloads grow, case managers take on more and more work. Stress and burnout among case managers is not uncommon. Enhanced support for case managers, including better coordination and training, is needed. Support staffing, in the form of a senior case manager, should be considered.

A small number of consumers play an active role in the Consortium. Many consumers cited the need for empowerment and self-esteem building through community service. The Consortium must address methods of increasing consumer involvement in outreach and service delivery, through paid staff positions and volunteering. The need for a buddy system to support the newly diagnosed and to provide assistance to other consumers is evident.

The demand for support groups is growing, yet group leaders cite the difficulty of conducting groups in the presence of many young children. On site child care may be an option to this obstacle, as well as the under-utilization of the child care program in its present form. Access to medications and vitamins is also seen as critical.

Health care reform and entitlement eligibility restrictions affect access and service delivery. Many providers fear that fewer services will be available, often on an emergency basis only. Reimbursements may limit the degree of care provided to consumers. The lack of supported housing for people with AIDS is also seen as a threat to providing care. Consumers rate housing as one of their most pressing needs.

The Consortium has an opportunity to create a comprehensive care system in Holyoke, Chicopee and Westfield from the ground up, building upon already existing services and expanding to meet needs as they emerge. Through expanding Consortium membership, increased involvement of consumers in the Consortium, and coordination of information, referral and care, HIV services will continue to improve.

ONGOING MONITORING AND EVALUATION.

The monitoring process is designed to be implemented by Consortium staff, without assistance from an outside consultant. Should help or support be needed, the Donahue Institute can provide technical assistance to the Consortium (contingent upon the availability of funding). However, the monitoring process can be implemented without such assistance.

The purpose of the ongoing monitoring process is:

1. to enable the Consortium to evaluate its ability to meet the current and emerging service delivery needs in the community;
2. to develop programmatic responses to address unmet needs;
3. to produce an annual report of the process of data collection and analysis used for program development and improvements in service delivery.

Many of these activities already occur both informally and formally. The results of the needs assessment presented in this document provide the baseline for future comparisons.

Ongoing monitoring will be an integral part of ongoing Consortium activities and will include components designed to assess the process of service delivery and the outcome of service and coordination initiatives.

Consortium members will support evaluation activities through their knowledge of the kinds of utilization data their respective agencies and organizations can provide, by offering the Lead Agency their expertise on specific access and service issues, and by facilitating access to data from other sources. Consortium members will work with the Lead Agency to ensure that a detailed description of access and utilization of services by consumers is obtained.

The ongoing monitoring process will be twofold:

1. programmatic monitoring/evaluation
2. ongoing needs assessment to monitor changing needs in the community with regard to HIV and AIDS.

The Consortium will obtain feedback from organizations and service providers and consumers with regard to salient issues surrounding access, utilization and delivery of services. Documentation of the schedule and extent of utilization of services and fiscal expenditures for same will allow comparison of the actual delivery of services to the proposed plan, and provide data regarding necessary modifications and service needs. Administrative procedures utilized to

oversee Consortium activities will be examined and refined, as necessary. Comprehensive case management approaches and service delivery strategies will be examined to facilitate future attempts to expand or broaden Consortium activities.

Description of Existing Conditions.

The needs assessment established the range of perceptions of problems and needs as well as the current state of service delivery addressed by Consortium activities. This description of the initial status of coordination and delivery of services will be used as the baseline against which future process descriptions (and outcome measures) will be compared.

Program Monitoring.

The Lead Agency will utilize specific procedures designed for monitoring the implementation of Consortium activities. Monitoring activities will include:

- documentation of all meetings of the Steering Committee, sub-committees, case managers and the Consumer Advisory Board, through the use of a standard report form, delineating topics discussed, issues or problems raised, and decisions or action steps agreed upon;
- data collection instruments, derived from the initial consumer and provider questionnaires, will be administered to Consortium members, case managers and consumers on an annual basis to routinely track changing and emerging service needs;
- collection, review and analysis of archival materials, i.e., allocation of resources, utilization data, reimbursements for services, etc.

Outcomes will be compared against baseline data gathered by the needs assessment to evaluate the extent to which the successes of outreach and coordinated case management and service delivery efforts can be measurably linked to specific increases in enhancement, expansion, access, coordination, and utilization of services for people with HIV and AIDS. Outcome data will be collected in conjunction with Consortium members, using instruments designed to coordinate data collection from service providers, consumers and other data sources deemed relevant to the monitoring process.

MONITORING PHASES.

Monitoring will be conducted in five inter-related phases, as described below.

- PHASE I. Review of finding from the needs assessment report prepared by the Donahue Institute (July, 1993)
Baseline data/Description of existing conditions
- PHASE II. Review of administrative oversight procedures
Resource allocation, reimbursement, etc.
Coordination of Consortium activities
Training and support received by Case Managers
- PHASE III. Consumer, case manager and provider input
Surveys, interviews and/or focus groups
Data analysis
- PHASE IV. Identification of opportunities for improvement
Implementation of improvement strategies
- PHASE V. Assessment of success of improvements
Comparisons of outcome to baseline measures
Suggestions for continuous quality improvement

APPENDIX A
NEEDS ASSESSMENT INSTRUMENTS

QUESTIONS FOR CONSORTIUM REPRESENTATIVES

Organization:

Representative:

Date of Interview:

Interviewer:

What HIV Care Services are provided by your agency?

Which services are in most demand? (among whom?; where?)

Which services, if any, are under-utilized?

What are the most frequent barriers to service encountered by your clients?

What methods are used to negotiate the system or work around these obstacles? (by consumers/by case managers?)

If you had more financial resources available, which services would you expand or add?

What feedback do you receive from consumers regarding your services?

Are consumers involved in the development of new programs or services?

How would you change/expand the role of consumers in service development/delivery?

What types of community outreach does your agency conduct?

What are the main issues facing your agency with regard to service delivery?

How has this changed over the last few years?

What do you see as the most pressing community needs? (If dual members, ask about both Spfld. and H/C/W)

How do these needs differ with regard to age, gender, race/ethnicity, sexual orientation?

How can these needs be better addressed?

What do you see emerging as the most pressing needs over the next five years?

How has your agency benefitted from membership in the HIV Care Consortium (or both, for dual members)?

What changes would you like to see in services, coordination, etc., provided by the Consortium?

How would you like to see new funding allocated? Which services would you target?

Are there additional issues that you would like us to know about?

QUESTIONS FOR CONSUMERS

Circle one:
Case Manager
Consumer Group
Individual Consumer
Consumer Advisory Board

Are people with HIV/AIDS aware of the care services available to them?

How do people with HIV/AIDS learn about available services?

How can providers get the word out about what they have to offer?

Which services are the most helpful?

Which services are the least helpful?

What services do you think are needed that are not available?

What services would you like to see offered or expanded?

What difficulties or problems make it hard to get services?

What would make it easier?

How can consumers voice concerns about treatment or prevention?

How can services be better coordinated?

How can consumers work with providers to let them know what their needs are to improve services?

If you worked as a service provider, how would you change the system?

Please answer a few more questions about yourself, circling all that describe you (OPTIONAL):

Age group: under 18 19-25 26-35 36-45 over 45

Latino	African-American	White, non-Latino
Asian-American	Southeast Asian	Cape Verdean
African-Caribbean		

Male OR Female?

Do you have children under 18? How many?

Sexual Orientation? IV Drug User?

Other information you think we should know about you?

PREGUNTAS PARA LOS CONSUMIDORES

Circle one:
Case Manager
Consumer Group
Individual Consumer
Consumer Advisory Board

Estan las personas con SIDA y HIV enteradas de los servicios disponibles para ellos?

Como se enteran las personas con SIDA y HIV de los servicios disponibles?

Como pueden los proveedores de servicios dar a conocer los servicios que ellos ofrecen?

Cuales son los servicios que mas ayudan?

Cuales son los servicios que menos ayudan?

Que servicios usted considera necesarios y no estan disponibles?

Cuales servicios le gustaria que se ofrecieran o que se expandieran?

Que dificultades o problemas hacen dificil el conseguir los servicios?

Tiene alguna sugerencia de como mejorar ese problema o dificultad?

Como se pueden coordinar mejor los servicios?

Como pueden trabajar los consumidores, con los proveedores de servicios, para dejar saber sus necesidades para el mejoramiento de los servicios?

Como pueden los consumidores expresar sus preocupaciones en relacion a tratamiento y prevencion?

Si usted trabaja como proveedor de servicios, como usted cambiaria el sistema?

Por favor conteste estas preguntas relacionadas a su persona, circulando todas aquellas que le describe:

Edad: menor de 18 años 19-25 26-35 36-45 mayor de 45

Latino/a Africano-americano Blanco - no latino

Asiatico-americano Suroeste de Asia Caboverdiano

Masculino Femenino

Tiene niños menores de 18 años de edad? Cuantos?

Preferencia Sexual:

Usuario de drogas:

Alguna otra información que usted considera que debemos saber acerca de usted?

QUESTIONS FOR USE BY BRIDGE WORKERS

1. How do people with HIV or AIDS find out about services available to them?
2. What do people you know who have HIV or AIDS say about services?
3. How can agencies get the word out about HIV and AIDS services they offer?
4. What kinds of things make it hard for people who have HIV or AIDS to get services?

1. HIV CARE SERVICES PROVIDED BY AGENCIES (N=18)				
	H/C/W members	dual members		
	n=11	n=7		
HEALTH				
counseling & referrals	27.27%			
alternative test site	9.09%	14.29%		
nutrition	9.09%			
dental care	9.09%			
Act NOW		14.29%		
primary health care	9.09%			
HOME HEALTH CARE	27.27%	28.57%		
PT,OT, speech therapy	27.27%			
home health aide	18.18%			
skilled nursing	27.27%			
homemaking	9.09%			
IV therapy (infusion, drug)	9.09%	14.29%		
respiratory therapy		14.29%		
MENTAL HEALTH				
HIV+ therapy	9.09%	14.29%		
family therapy	9.09%			
SUBSTANCE ABUSE				
dual diagnosis SB & HIV	9.09%			
SUPPORT SERVICES				
case management	18.18%	57.14%		
discharge planning	9.09%			
social work	9.09%			
child development	9.09%			
child groups	9.09%			
support services	9.09%			
family support	9.09%			
adult family day care	9.09%			
HIV support groups		14.29%		
pastoral care		14.29%		
outreach		28.57%		
Buddies program		14.29%		
emergency assistance \$		14.29%		
residential SRO's		14.29%		
EDUCATION/PREVENTION		28.57%		
HIV education groups	9.09%			
health education	9.09%			
provider education & training	18.18%	14.29%		
SERVICE DELIVERY SUPPORT				
coord. services w/case mgrs		14.29%		
case mgr training/support		14.29%		
program/service development		14.29%		
POLITICAL ASPECTS OF CHANGE	9.09%			

TABLES: Provider Responses

[illegible]

TABLES: Provider Responses

[illegible]

4. MOST FREQUENT BARRIERS TO SERVICE (N=18)				
	H/C/W members	dual members		
	n=11	n=7		
ACCESS				
reimbursement - uncov. services	9.09%	14.29%		
dual diagnosis SA & AIDS	9.09%	28.57%		
available substance abuse treat.	9.09%	14.29%		
few sites available for treatment	18.18%			
unwilling to provide HIV services	18.18%			
too few services to meet demand	9.09%			
few docs in Chic. or Wfld. accept Medicaid	18.18%			
PWA awareness of avail. services	27.27%	14.29%		
cost and concept of dental care	9.09%			
no services for hearing-impaired	9.09%			
feeling disenfranchised		14.29%		
little, no targetted support groups		14.29%		
home environment not conducive to home therapies		14.29%		
home therapies not suitable for IV substance abusers		14.29%		
no pref for PWA's in substance abuse treatment, even w/\$		14.29%		
STRUCTURAL				
coordination of services	9.09%			
not enough case mgrs		14.29%		
case mgr case loads too large		14.29%		
TRANSPORTATION	27.27%	28.57%		
too sick to use public transportation	18.18%			
distance to travel for treatment	9.09%			
LANGUAGE/CULTURE				
language	18.18%	28.57%		
provider cultural sensitivity	18.18%			
lack of biling./bicult. professionals	9.09%	14.29%		
cultural		28.57%		
issue of death in Latino culture	9.09%			
PWA refusal, cancelling apptments.	9.09%			
avoid personal care services	9.09%			
stigma attached to HIV/AIDS	9.09%			
delay treatment due to fear of disclosureprivacy issues	18.18%	14.29%		
family members - lack of support		14.29%		
POLITICS/COMMUNITY				
little city \$ support		14.29%		
politics, infighting among providers	9.09%			
little city support for street outreach, condom distr., etc.	9.09%	14.29%		
politics and community support	9.09%	14.29%		

[illegible]

6. IF MORE \$, EXPAND OR ADD SERVICES (N=18)				
	H/C/W members	dual members		
	n=11	n=7		
HEALTH				
nutritional		28.57%		
non-traditional medicine		28.57%		
hospice		14.29%		
substance abuse treatment		42.86%		
massage therapy		28.57%		
pain management		14.29%		
RN - coordinate services for PWA	18.18%			
home health care	9.09%	14.29%		
medical services	9.09%			
ATS	18.18%			
HIV counseling	9.09%			
SUPPORT SERVICES				
case management services	9.09%	14.29%		
case management position	9.09%			
counseling/support		28.57%		
meals on wheels	9.09%			
targetted services*	27.27%			
volunteer PWA network to work				
w/newly diagnosed	9.09%			
support groups	18.18%			
accessible childcare	9.09%			
legal services		14.29%		
housing		28.57%		
\$ management for PWA's		14.29%		
ACCESS				
free care		14.29%		
\$ for medication for uninsured	9.09%			
increase entitlement benefits		14.29%		
reimbur. for homemaking services	18.18%			
fill gaps in elig. for adult family care	9.09%			
EDUCATION/PREVENTION	45.45%			
ed around benefits of dental care	9.09%			
outreach	9.09%			
TRANSPORTATION	27.27%	28.57%		
agency van/driver	9.09%	14.29%		
PVTA bus passes	9.09%			
sm. case load - don't know	9.09%			
* for Latino gay men, single women, mothers w/ HIV				

7. FEEDBACK FROM CONSUMERS RE: SERVICES (N=18)			
	H/C/W members	dual members	
	n=11	n=7	
MECHANISMS			
tell case managers	9.09%		
tell providers	9.09%		
through interviews/surveys	36.36%		
NEGATIVE			
case loads too large		14.29%	
they want treatment on demand	9.09%		
too much \$ spent on administration	9.09%		
dislike long waiting time in clinics	9.09%		
they don't understand long waits			
are due to short staffing	9.09%		
they take out upsets w/welfare regs			
on staff	9.09%		
they think providers can do more			
than is possible	9.09%	14.29%	
POSITIVE	18.18%		
case mgmt services are helpful		14.29%	
referrals are helpful		14.29%	
they come back & bring friends	9.09%		
services are helpful	9.09%	42.86%	
education re: prevention good		14.29%	
NEEDS			
transportation		14.29%	
links to other providers/services	9.09%		
housing services	9.09%	14.29%	
NO FEEDBACK	9.09%	14.29%	
8. CONSUMER INVOLVEMENT - NEW PROGRAM/SERVICE DEVELOPMENT (N=18)			
	H/C/W members	dual members	
	n=11	n=7	
N/A	45.45%	14.29%	
through advisory boards,			
committees or councils	54.55%	57.14%	
incidentally (if they happen to be			
on the Board of Directors)	9.09%		
through case mgr input		14.29%	
in all endeavors		14.29%	
fear of disclosure a barrier		14.29%	
would like more consumer involv.	9.09%		

[illegible]

[illegible]

11. MAIN ISSUES FACING YOUR AGENCY RE: SERVICE DELIVERY (N=18)				
	H/C/W members	dual members		
	n=11	n=7		
HEALTH ISSUES				
patient assessment		14.29%		
environment for home therapies		14.29%		
acceptance of nursing in non-trad				
role - community education		14.29%		
medicaid constraints	18.18%			
managed care	18.18%			
reimb. doesn't cover time needed				
to provide services to PWA's	9.09%			
time of referral for care		14.29%		
dual diagnosis		28.57%		
growth in HIV among teens		14.29%		
RESOURCES				
uninsured clients	9.09%			
having adequate \$	27.27%	14.29%		
adequate transportation \$	9.09%			
soft \$ runs out	9.09%			
public health dept. budget cuts	9.09%			
ACCESS				
consumer awareness of services	9.09%	14.29%		
lg. case loads affect cont. of care	9.09%			
too few services avail. in area	18.18%			
need programs for gay men, single				
women w/children	9.09%			
must improve serv. to Latino comm.	9.09%			
serving lg. biling/bicult. population	9.09%			
hard for clients to meet own needs	9.09%			
PROVIDERS				
under-staffing		28.57%		
case loads too large		14.29%		
attracting/retaining staff	9.09%			
define/standardize role of case mgr		14.29%		
finding reimb. eligible bil/bic staff	9.09%			
provider training re: HIV		14.29%		
inter-agency communication		14.29%		
staff training		14.29%		
CONSORTIUM				
too much \$ for administration	9.09%			
turf issues (\$ and services)	9.09%	14.29%		
flexibility and willingness to change	9.09%			
small population now, will change	9.09%			

[illegible]

13. MOST PRESSING COMMUNITY NEEDS (N=18)				
	H/C/W members	dual members		
	n=11	n=7		
HEALTH				
continuity of care	18.18%			
better health care	9.09%			
services in Holyoke, Chic. and Wfld	18.18%			
access to HIV testing	9.09%			
counseling/mental health	18.18%			
substance abuse treat. on demand	27.27%	28.57%		
home health care		14.29%		
services for dual diagnosis	18.18%			
consumer adapt. to treat. needs		14.29%		
SUPPORT SERVICES				
support group for Anglo males	9.09%			
for families w/parents w/AIDS		14.29%		
for women & children w/AIDS	9.09%			
HIV services	18.18%			
companion prog for elders	9.09%			
adequate, affordable housing	18.18%	28.57%		
transportation	36.36%			
meals	9.09%			
supported daycare for work/school	18.18%			
part-time work w/benefits	9.09%			
ENVIRONMENT/SOCIAL	18.18%			
self esteem building		14.29%		
community service		14.29%		
rising HIV amg urban women		14.29%		
chaotic home situations	9.09%			
outreach	18.18%			
teen pregnancy	9.09%			
crime/incarceration	18.18%			
ACCESS				
cultural barriers	9.09%			
language barriers	9.09%			
consumer awareness of services		14.29%		
EDUCATION/TRAINING		14.29%		
literacy		14.29%		
supported ed/trng to get off AFDC	18.18%			
for consumer compliance w/treatmt		14.29%		
cultural sensitivity training		28.57%		
EDUCATION/PREVENTION	18.18%			
K-12 HIV curriculum in Mass.	9.09%	14.29%		
HIV education	45.45%			
education on testing	9.09%			
RESOURCES				
\$ for providers		14.29%		
\$ for PWA's		14.29%		

[illegible]

[illegible]

16. MOST PRESSING NEEDS - NEXT FIVE YEARS (N=18)				
	H/C/W members	dual members		
	n=11	n=7		
HEALTH				
in-home palliative care by RN's	18.18%	14.29%		
PWA's live longer, needs will rise	36.36%			
higher demand for acute care	9.09%			
mng'd care limits on extent of care	9.09%			
substance abuse services	9.09%	14.29%		
high-tech home therapies		14.29%		
massage therapy		14.29%		
nutritional support		28.57%		
flexibility in changing h.c. economy		14.29%		
long-term care options		28.57%		
ACCESS	18.18%	28.57%		
people will delay treatment	9.09%			
rationing of health care \$ for AIDS	9.09%	14.29%		
uninsured will only rec'v emergency				
treatment	18.18%	14.29%		
eligibility restrictions - drop in				
preventive care	9.09%	14.29%		
\$ to meet demand for services	27.27%			
gaps in service due to demand	27.27%			
informing people about services	9.09%			
EDUCATION/PREVENTION				
early intervention	9.09%			
prevention	9.09%			
public health ed re: epidemic	27.27%			
work around religious opposition	9.09%			
involving families in AIDS education	18.18%	14.29%		
staff ed on death & bereavement	9.09%			
providers on cultural sensitivity		14.29%		
SUPPORT SERVICES				
more case mgmt		14.29%		
more outreach		14.29%		
living center		14.29%		
housing options		28.57%		
access to transportation	9.09%	14.29%		
legal assistance		14.29%		
volunteers		14.29%		
RISING #'S	27.27%			
Latino comm - due to IV drug use	9.09%			
heterosexual transmission	18.18%			
pediatric AIDS growth	9.09%	14.29%		
teens, young adults w/AIDS	9.09%	14.29%		
families w/ members w/AIDS	27.27%	28.57%		
orphaned children		28.57%		
people alone, no family supports	9.09%			

[illegible]

18. PROPOSED CHANGES RE: CONSORTIUM SERVICES, COORDINATION... (N=18)				
	H/C/W members	dual members		
	n=11	n=7		
RESOURCES				
access to more \$	18.18%			
allocate \$ to reflect consumer need	9.09%			
move admin \$ to services	9.09%			
move case mgr \$ to transportation	9.09%			
allocate more \$ to oversight	9.09%			
better monitoring of \$	27.27%			
more flexibility in spending \$		14.29%		
stretch transp \$, e.g., agency van		14.29%		
STRUCTURE/PROCESS				
standardization of services		14.29%		
more focus on realities of care		14.29%		
greater consumer involvement	18.18%			
stronger commitment to network	9.09%			
less duplication of services*	18.18%			
broaden rep providers/people	18.18%			
autonomous sr. case mgr position		14.29%		
CONSUMER NEEDS				
needs of diverse populations		14.29%		
more input from case managers		14.29%		
periodic update of needs asmt	9.09%			
look at emerging consumer needs		14.29%		
SERVICES				
increase referrals for fam counsel.	9.09%			
more outreach to consumers	9.09%			
more support groups	9.09%			
expand services	9.09%			
offer home-making services	9.09%			
establish service base in Westfield	18.18%			
housing services		14.29%		
dental care		14.29%		
recreation		14.29%		
EDUCATION				
case manager training	9.09%			
info to consumers re: services	18.18%			
ed. re: child care \$ available		14.29%		
consumer awareness of need,				
benefits of family counseling	18.18%			
*w/out compromising confidentiality, anonymity				

19. NEW FUNDING, TARGETTED SERVICES (N=18)				
	H/C/W members	dual members		
	n=11	n=7		
HEALTH				
home palliative care	9.09%			
home-making services	9.09%			
nutritional support		14.29%		
long-term care		14.29%		
access to services	9.09%			
STRUCTURE				
F/T pd. position to increase,				
support consumer involvement	9.09%			
more case mgr involvement		14.29%		
find a better day care model	18.18%	14.29%		
monitoring of transportation \$	9.09%			
ALLOCATION OF \$				
more frugality		14.29%		
to orgs who can best deter. needs		14.29%		
flex. in alloc. and use accg to need	9.09%	14.29%		
transportation	45.45%			
food, home delivered meals	27.27%			
discretionary \$	9.09%			
monitoring	9.09%			
vitamins/OTC medications		28.57%		
accg to #'s served		14.29%		
less \$ for child care	9.09%			
more \$ to grassroots effort		14.29%		
\$ for partner to provide home care	9.09%			
SUPPORT SERVICES		14.29%		
housing mediation		14.29%		
legal services		28.57%		
support groups	18.18%			
increase awareness\referral for				
family counseling	9.09%			
more emphasis on impact of AIDS				
on loved ones	9.09%			
living center		14.29%		
consumer community service		28.57%		
increase consumer self-esteem		14.29%		
address emerging needs		14.29%		
OUTREACH	18.18%			
consumer outreach	9.09%			
pediatric case mgr outreach to				
agencies serving families	9.09%			
EDUCATION/PREVENTION	18.18%			
substance abuse prevention	9.09%			
more literature in Span. and English	9.09%			
creative HIV ed. (not preaching)	9.09%			

20. ADDITIONAL ISSUES (N=18)				
	H/C/W members	dual members		
	n=11	n=7		
DAY CARE \$				
need drop off center	9.09%			
hard to make prior arrangements	9.09%			
transp. adds to low usage	9.09%			
CONSUMERS				
focus on negative, overlook pos		14.29%		
lack of communication btwn				
cons & prov - misinformation		14.29%		
involve, empower - inc. self esteem		14.29%		
PROVIDERS				
need earlier referrals from docs		14.29%		
private docs lack knowledge,				
training on HIV, AIDS	9.09%			
docs don't know services available	9.09%			
turf battles impede delivery	9.09%			
no support for case managers	9.09%			
stigma in working in AIDS field		14.29%		
RESOURCES				
ACT Now \$ too low, runs out	9.09%			
gaps btwn ACT Now and free care	9.09%			
disincentive to avoid infection -				
then needs are covered	9.09%			
CONSORTIUM				
not sure lead agency model best	9.09%			
need regular, permanent coord.	9.09%			
not enough admin \$ to run right	9.09%			
must avoid distancing fr consumers	9.09%			
POLITICAL				
limits on education in the schools	9.09%			
limits on condom distr, etc.	9.09%			
COMMUNITY				
church need to be more active	9.09%			
talk about living with AIDS	9.09%			
denial, "it won't happen to me"	9.09%			

APPENDIX C

CASE MANAGER AND CONSUMER RESPONSES

1. CONSUMER AWARENESS OF SERVICES			
	Case Mgrs	Consumers	CAB Members
	n=6	n=24	n=3
Yes	33.33%	25.00%	
No		33.33%	33.33%
Some are aware		29.17%	
Most are aware	16.67%		
Most are not aware		4.17%	66.67%
Yes, after intake	16.67%		
Few are aware of all avail. services	33.33%		
2. LEARNING ABOUT SERVICES			
	Case Mgrs	Consumers	CAB Members
	n=6	n=24	n=3
COMMUNICATION	16.67%		33.33%
word of mouth	16.67%	16.67%	
friends	16.67%	12.50%	
relatives	16.67%		
other consumers		16.67%	
HEALTH CARE SYSTEM	16.67%		
hospital	16.67%	4.17%	
clinics		4.17%	
visiting nurses	16.67%	4.17%	
doctors		16.67%	
nurses		4.17%	
when ill		4.17%	33.33%
SUBSTANCE ABUSE PROGRAM	16.67%		
methadone program	16.67%	4.17%	
detox	16.67%		
SUPPORT SERVICES	16.67%		
providers	20.83%		
intake	16.67%		
case managers		25.00%	
support groups		20.83%	
social workers		4.17%	
CONSUMERS			
at appointments			33.33%
reading materials		4.17%	
meetings		12.50%	33.33%
MEDIA			
flyers		4.17%	
newspaper		4.17%	
notices at provider offices		4.17%	

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4. EXPAND OR OFFER SERVICES			
	Case Mgrs n=6	Consumers n=24	CAB Members n=3
SUPPORT SERVICES			
case management		8.33%	33.33%
support groups			33.33%
English language support groups	16.67%		
bereavement counseling	16.67%		
stress management	16.67%		
more programs for HIV		4.17%	
more women's programs		4.17%	
programs for families w/HIV parent		4.17%	
child care	16.67%	12.50%	
housing		16.67%	
misc. financial assistance	16.67%		
RECREATION			33.33%
place where PWA's can talk			33.33%
hobby shop			33.33%
activities		4.17%	
HEALTH CARE			
over the counter medications			33.33%
more doctors to treat HIV		4.17%	
more dentists to treat people w/HIV		4.17%	
dual diagnosis		8.33%	
methadone treatment		12.50%	
holistic medicine		4.17%	
TRANSPORTATION	33.33%	16.67%	
staff & volunteers for transportation		8.33%	
NUTRITION			
emergency foodbank access			33.33%
home delivered meals		8.33%	33.33%
CONSORTIUM			
volunteer coordinator	16.67%		
networking		4.17%	
bilingual services	16.67%		
information on services/medication		8.33%	
EDUCATION/PREVENTION	16.67%		33.33%
prevention interventions	16.67%		33.33%
materials in Spanish	33.33%		

5. MOST HELPFUL SERVICES			
	Case Mgrs	Consumers	CAB Members
	n=6	n=24	n=3
HEALTH CARE	16.67%	12.50%	
medicine		4.17%	
home health aides	16.67%		
information on new med services		4.17%	
information on new drugs		4.17%	
translation services	16.67%		
interpreters	8.33%		
TRANSPORTATION	83.33%	29.17%	33.33%
taxis		8.33%	
SUPPORT SERVICES			
child care	16.67%	4.17%	
buddy program	16.67%		
ongoing case management	16.67%	12.50%	33.33%
social work			33.33%
counseling		16.67%	
providers		16.67%	
women's group		4.17%	
group counseling		4.17%	
meals	16.67%	4.17%	33.33%
welfare		4.17%	
affordable or supported housing	83.33%		
6. LEAST HELPFUL SERVICES			
	Case Mgrs	Consumers	CAB Members
	n=6	n=24	n=3
SUPPORT SERVICES			
child care program	33.33%	4.17%	
home delivered meals	33.33%		
welfare		8.33%	
DSS		4.17%	
employment services		8.33%	
BARRIERS			
long wait for transportation	16.67%	4.17%	
long wait for services		4.17%	
long housing waiting list	16.67%		
DON'T KNOW		20.83%	100.00%

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[illegible]

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13. CHANGING THE SYSTEM			
	Case Mgrs	Consumers	CAB Members
	n=6	n=24	n=3
HEALTH CARE			
socialize medicine	16.67%		
STAFFING			
MSW trained in death and dying	16.67%		
case mgr supervisor	16.67%		
burn out prevention	16.67%		
staff empathy, sensitivity		4.17%	
CONSUMER INVOLVEMENT			
more consumers in service jobs		4.17%	66.67%
consumers work w/consumers			33.33%
consumer volunteer to keep busy			33.33%
PROVIDERS			
more people to service community		8.33%	
improve communication	16.67%		
more meetings w/consumers	16.67%	4.17%	
assist PWA's to meet needs		8.33%	
faster access to services		4.17%	
community-based services		4.17%	
develop needs questionnaire	16.67%		
SUPPORT SERVICES			
do not divide by race/ethnicity		4.17%	
more support meetings		4.17%	
foster child care	16.67%		
\$ for HIV housing	16.67%	4.17%	
more \$ for services	33.33%		
more \$ for transportation		4.17%	
INFORMATION			
information meetings	16.67%		
more information		4.17%	
COMMUNITY			
welcome people w/HIV and AIDS		4.17%	
increased communication		8.33%	

APPENDIX D
BRIDGE VOLUNTEER INTERVIEW RESPONSES

SEX INDUSTRY WORKER RESPONSES

1. LEARNING ABOUT AVAILABLE SERVICES		
	n=5	
MEDIA		
written	20.00%	
television	20.00%	
pamphlets in neighborhood	20.00%	
WORD OF MOUTH	40.00%	
friends who are HIV positive	20.00%	
doctor	20.00%	
after infected	20.00%	
800 number	20.00%	
avoid information out of fear	20.00%	
2. WHAT PEOPLE W/HIV OR AIDS SAY ABOUT SERVICES		
	n=5	
PROVIDERS		
staff rudeness	20.00%	
lack of respect in treatment	20.00%	
3. GETTING THE WORD OUT		
	n=5	
MEDIA		
TV and media do not work	20.00%	
more and different sources	20.00%	
MARKETING		
brochures/flyers	20.00%	
intensive promotion of services	20.00%	
OUTREACH	20.00%	
word of mouth	20.00%	
street outreach	40.00%	
4. BARRIERS		
	n=5	
TRANSPORTATION	20.00%	
ACCESS		
lack of \$	20.00%	
no insurance or medicaid	40.00%	
unwillingness to accept services	20.00%	
procrastination/delay of treatment	20.00%	
agencies can't force receipt of		
services	20.00%	
COMMUNITY		
public doesn't understand HIV	20.00%	
bigotry against HIV status	20.00%	

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